

Changes in Mood & Behavior

Understanding shifts in mood and behavior

- Causes
- How to respond
- Common feelings



How to Respond

Persons living with memory loss are very individual in how these diseases will affect their mood and behavior. For some individuals, there is a loss of enthusiasm and interest in life. Others may experience frequent mood swings, with angry or suspicious outbursts.

These shifts are the result of changes in the brain and are as unexpected and upsetting to the person as they are to the family. As one man with Alzheimer's disease said, "Half the time we don't know why we are acting the way we are – so how are they supposed to know?" Another said, "I feel the anguish between my wife and me."

Am I doing good enough most of the time?
If the answer is yes, then you're doing a good job!

Few of us are natural caregivers. It is a learning process and things will continue to shift over time. Try to be especially kind to yourself as you grow in understanding and patience. Trust in yourself. You will be able to find the answers you are looking for and the resources you need to live with these changes.

Possible Causes of Changes in Behavior

Physical

- Medication
- Dehydration
- Acute illness, e.g. fever, urinary tract infection
- Fatigue

Emotional

- Frustration
 - Inability to understand what is being said
 - Inability to make oneself understood
 - Inability to do something

- Fear
- Loss of dignity
- Depression

Environmental

- Over-stimulation
- Under-stimulation
- Lack of structure or cues
- Change of routine, caregiver, living situation

Task Related

- Too complicated (too many steps)
- Unfamiliar

What to Do

- Acknowledge thoughts or feelings by validating and rephrasing words.
 "You're thinking about ____."
 "You seem angry."
- Reassure
 "No matter what happens, I'll always be there for you."
 "I'm so sorry this has happened to us, but we've made it through some pretty tough times. We'll get through this together."
- Redirect
 "Let's sit for a minute and have a cup of tea."
 "Why don't we take a break and search for that bill later. I'll put some music on."
 "Let's go for a walk before lunch. After lunch, we'll figure out what to do about____."
 "I could use a break. How about if we take a ride in the car? It's such a nice day."
- If someone is extremely agitated or upset:

1. Approach from the front
2. Position yourself at person's eye level
3. Speak slowly and softly
4. Use eye contact
5. Use short simple sentences

What happens is not as important as how you
react to what happens. *Thaddeus Golas*

TRY NOT TO:

1. Argue
2. Question
3. Correct
4. Convince
5. Take the behavior or accusation personally

Tips on Communication

Memory loss can affect the giving as well as the receiving of information. The words you use are only one piece. There is a whole underlying emotional message seen through your facial expression, tone of voice, and body posture that can be much more important than any words you choose.

Ninety-three per cent of communication is non-verbal.

When you have important information to give:

- Talk **face to face** - with good eye contact.
- **Limit distractions**, like the TV, to ensure the person's full attention.
- **Use nouns** when giving information. They're the name of the game! Repeating these key nouns helps the person hold on to what you are saying.

It's easy to fall into the habit of talking at rather than with someone who has memory loss. This is usually task-oriented conversation, such as, "Did

you shave this morning” or “There’s a sandwich in the fridge”, or “You need a jacket today”.

Keeping the person connected through social conversation is vitally important. It can be as little as five seconds. For example, “I really like it when you help with the dishes.” It is sharing personal information, feelings, preferences, and experiences. **It’s the human connection!**

Common Reactions: The Top Three!

ANGER

GUILT

SADNESS

Families feel angry about:

- Family members who won’t admit there’s any problem
- Family members who won’t help
- Person with illness won’t/can’t admit there’s any problem
- Person with the illness for not trying hard enough
- Loss of dreams for the future
- Why is this happening to us
- Having to take on so much responsibility
- The way doctors handled/are handling the situation
- Insurance coverage that doesn’t cover enough
- How person with illness is behaving
- Friends who don’t come around anymore

Families feel GUILTY about:

- Not doing a good job as a caregiver
- Taking time for themselves
- Feeling happy or laughing
- Being embarrassed of the person with the illness
- Feeling angry at the person with the illness
- Losing their temper/yelling
- Wanting the person with the illness to pass away

Families feel SAD about:

Loss of dreams for the future
Loss of companionship and sexual intimacy
Loss of an important relationship
Loss of friends
Seeing loved ones lose abilities or struggle with pain
Loss of income



Stress-Busting Techniques

Acceptance

Many of us worry about things that we have no control over. An important step to effectively managing your stress is to accept when things are beyond your control. When you can't do anything about a situation, practice "stress-busting self-talk", such as, "Someday I'll laugh about this", "I'll get better at this", or "Tomorrow is another day."

Attitude

Try to focus on the positive side of situations. Ask yourself, "What good can come out of this?", "What can I learn from this situation?", or "How can I handle this better if it comes up again?" By focusing on the positive, you'll find solutions come more easily and your stress level will be reduced.

Perspective

Too often, we worry or become upset about things that never happen. To keep things in perspective, ask yourself, "How important is this situation?" "Can I do anything about it?" "In five years, will I even remember it happened?"

A Daughter Reflects: What I'd do Differently

The pain of caring for someone with Alzheimer's disease is often unbearable. Looking back over the time I cared for my mother, I realize I made a lot of mistakes. These mistakes usually weren't harmful to my mother, but many of them were to me. Alzheimer's literature talks about the need for caregivers to take care of themselves. I know that's not easy, but if I had to do it again, I would do the following:

Get help early. I shouldn't have waited for a crisis to make decisions. For example, Mom was probably eligible for homemaker services long before we had them. I felt I could handle everything myself; in reality, I couldn't. My mother might also have entered adult day care much earlier. She might have benefited from the social contact, and I would have had a few extra hours to myself.

Pamper myself. I ran around doing endless errands, when they probably didn't really need to be done. I felt that I didn't have the money for luxuries, but I surely could have scraped together a few dollars to get my hair done or go to a movie – anything to get out of the house and focus on something pleasant.

Ask friends for help. When friends asked me if they could do anything, I almost always said no. I should have accepted their offers readily and with glee. If I had to do it again, I'd take the initiative and call friends and ask them to come stay with Mom for an hour. Friends probably don't always expect to be taken up on their polite offers, but the worst they can do is decline.

Learn to live day by day. I worried and worried about what the future would bring. Projecting the next problem isn't productive. I should have realized how lucky Mom and I were to have a good day. Alzheimer's is not all a negative experience. There were many times when Mom and I shared a special closeness, which I will never forget.



Please note the brochure included in your handouts, entitled, *Behaviors*. It offers many excellent tips on anxiety, repetition, suspicion and other changes in behavior that may occur.

Call the Alzheimer's Association Helpline for additional tips at 216-721-8457 or 800-272-3900 or go online [www: alz.org](http://www.alz.org): note the purple bar at the top and click on resources. The section under *Fact Sheets* offers many additional tips.

**Specialized Information Packets Available
Through our Helpline**

Information about Repetition

Information about Sleeping

Information about Verbal and Physical Aggression

Information about Sundowning and Shadowing

Information about Paranoia and Delusions

Recommended Booklets and Books

Mace, Nancy, MA, and Rabins, Peter, MD, The 36-Hour Day, The John Hopkins University Press, 1999.

Koenig Coste, Joanne, Learning to Speak Alzheimer's, First Mariner Books, 2004.

Robinson, Anne, Spencer, Beth, and White, Laurie, Understanding Difficult Behavior, Geriatric Education Center of Michigan, 313-487-2335, 1996.

Roche, Lyn, Coping with Caring, Elder Books, 1996.

Brilliant Insights on Common Reactions From Persons Living with Memory Loss

1. Its hard to ask for help. I've always been so independent.
2. I'm losing words – but not cuss words!
3. There's a lot of pain to it – someone taking your privileges away.
4. I used to be the strong one. It's hard to accept when I can't do everything like I used to.
5. I'm angry! I can't accept all of this.
6. My daughter thinks she's the mother and I'm the daughter!
7. I can be trusted more than you think.
8. We must find ways to see areas of conflict as funny, instead of tragic.
9. I don't ask for too much help. I don't want to be a burden, or a bother.
10. Sometimes people look right through you.
11. My husband and I are getting on each other's nerves.
12. Its hard when you're there all the time. I need some leeway.
13. I get upset that I have to have my wife remind me of things. I'm not the man I used to be.

We seem to get bogged down in what we can no longer do.
I like to think about what I can still do – with no help.
In fact, I made a list!

14. The important thing is hanging in there when you can't change what's happening.
15. Sometimes I say to myself, tomorrow is another day.
16. I feel the anguish between my wife and me.
17. Sometimes I get so angry at forgetting, I want to smash the project I'm working on.
18. My problem is that I feel left out sometimes. I want to say, "Hello, I'm here!"
19. Half the time we don't know why we are acting the way we are – so how are they supposed to know?
20. We have to be honest with ourselves about our limitations.
21. I try to stay active and enthusiastic about doing things as much as I can.
22. I can do it myself; I want to do it myself.
23. I decided to have a "be good to Jane day".
24. He's not my caregiver – he's my husband
25. I'm convinced now that I have Alzheimer's disease; but I try to put it out of my head. I don't focus on what I forget; I just try to keep going.
26. I still feel very much a part of a loving family.
27. My dog understands every word I say; there would be a hole in our lives if she wasn't here.
28. Don't ever give up!

Blessed are
the Flexible
for They Shall
Not Be
Bent out of
Shape

Learning Together II Leaders Manual: Family Members

Focus: Moods and Behavior

Supplies:

Flip chart

Marker

Handouts for workbooks (3-hole-punched, paper clipped to take home)

Discussion handouts (copies at end)

1. Blessed are the Flexible, p. 12

1. Welcome individuals. If there are new people, ask each person to introduce themselves (without giving a snapshot view) and mention confidentiality.
2. Note the focus for this session is living with changes in moods and behavior. Set the tone by noting:
 - ✓How individualized each person is
 - ✓Few of us are natural caregivers! It's a learning process.
3. Pull specific difficulties families are experiencing now in moods or behavior, listing these on a flip chart. Note that we will be using this list for our discussion tonight.
4. Before leading into the first topic, note that these behaviors don't usually come out of the blue. There are many causes, which are covered in the handouts. For example:
 - ✓Physical: medication, dehydration, the flu
 - ✓Emotional: not able to get the words out
 - ✓Environmental: too much going on, rushing the person
 - ✓Task-related: too many choices
5. Cover one question or concern at a time, noting response on flip chart. If possible, begin each topic by asking the person who brought it up for a specific example. It's often wise to ask this person first for any things they have tried that were helpful.

As group discusses each item, look for ways to affirm useful techniques (listed in their handouts), e.g. telling your husband that you would look again for that bill after lunch was such a good idea. That technique is called redirecting the person. It's hard for a person to get out of anxious moments. They often get stuck on one idea. Taking a break and focusing on something else can help them get unstuck.

6. You may not be able to cover all the topics on your list. That's okay. What really matters is their growing sense that they will be able to find solutions for many of the things that are a concern to them.

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as how you react to what happens.

Thaddeus Golas

7. Note brochure in their handouts entitled, *Behaviors*. It covers additional behaviors and has many useful tips. Also, encourage them to call the Association's Helpline for more individualized ideas.
8. End on an upbeat note; pass out *Blessed are the Flexible*, p. 12.

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for They Shall
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